

105TH CONGRESS
1ST SESSION

S. 419

AN ACT

To provide surveillance, research, and services aimed at
prevention of birth defects, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE; FINDINGS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Birth Defects Prevention Act of 1997”.

1 (b) FINDINGS.—Congress makes the following find-
2 ings:

3 (1) Birth defects are the leading cause of infant
4 mortality, directly responsible for one out of every
5 five infant deaths.

6 (2) Thousands of the 150,000 infants born with
7 a serious birth defect annually face a lifetime of
8 chronic disability and illness.

9 (3) Birth defects threaten the lives of infants of
10 all racial and ethnic backgrounds. However, some
11 conditions pose excess risks for certain populations.
12 For example, compared to all infants born in the
13 United States, Hispanic-American infants are more
14 likely to be born with anencephaly spina bifida and
15 other neural tube defects and African-American in-
16 fants are more likely to be born with sickle-cell ane-
17 mia.

18 (4) Birth defects can be caused by exposure to
19 environmental hazards, adverse health conditions
20 during pregnancy, or genetic mutations. Prevention
21 efforts are slowed by lack of information about the
22 number and causes of birth defects. Outbreaks of
23 birth defects may go undetected because surveillance
24 and research efforts are underdeveloped and poorly
25 coordinated.

1 (5) Public awareness strategies, such as pro-
2 grams using folic acid vitamin supplements to pre-
3 vent spina bifida and alcohol avoidance programs to
4 prevent Fetal Alcohol Syndrome, are essential to
5 prevent the heartache and costs associated with
6 birth defects.

7 **SEC. 2. PROGRAMS REGARDING BIRTH DEFECTS.**

8 Section 317C of the Public Health Service Act (42
9 U.S.C. 247b–4) is amended to read as follows:

10 “PROGRAMS REGARDING BIRTH DEFECTS

11 “SEC. 317C. (a) IN GENERAL.—The Secretary, act-
12 ing through the Director of the Centers for Disease Con-
13 trol and Prevention, shall carry out programs—

14 “(1) to collect, analyze, and make available data
15 on birth defects (in a manner that facilitates compli-
16 ance with subsection (d)(2)), including data on the
17 causes of such defects and on the incidence and
18 prevalence of such defects;

19 “(2) to operate regional centers for the conduct
20 of applied epidemiological research on the prevention
21 of such defects; and

22 “(3) to provide information and education to
23 the public on the prevention of such defects.

24 “(b) ADDITIONAL PROVISIONS REGARDING COLLEC-
25 TION OF DATA.—

1 “(1) IN GENERAL.—In carrying out subsection
2 (a)(1), the Secretary—

3 “(A) shall collect and analyze data by gen-
4 der and by racial and ethnic group, including
5 Hispanics, non-Hispanic whites, Blacks, Native
6 Americans, Asian Americans, and Pacific Is-
7 landers;

8 “(B) shall collect data under subparagraph
9 (A) from birth certificates, death certificates,
10 hospital records, and such other sources as the
11 Secretary determines to be appropriate; and

12 “(C) shall encourage States to establish or
13 improve programs for the collection and analy-
14 sis of epidemiological data on birth defects, and
15 to make the data available.

16 “(2) NATIONAL CLEARINGHOUSE.—In carrying
17 out subsection (a)(1), the Secretary shall establish
18 and maintain a National Information Clearinghouse
19 on Birth Defects to collect and disseminate to health
20 professionals and the general public information on
21 birth defects, including the prevention of such de-
22 fects.

23 “(c) GRANTS AND CONTRACTS.—

24 “(1) IN GENERAL.—In carrying out subsection
25 (a), the Secretary may make grants to and enter

1 into contracts with public and nonprofit private enti-
2 ties.

3 “(2) SUPPLIES AND SERVICES IN LIEU OF
4 AWARD FUNDS.—

5 “(A) Upon the request of a recipient of an
6 award of a grant or contract under paragraph
7 (1), the Secretary may, subject to subparagraph
8 (B), provide supplies, equipment, and services
9 for the purpose of aiding the recipient in carry-
10 ing out the purposes for which the award is
11 made and, for such purposes, may detail to the
12 recipient any officer or employee of the Depart-
13 ment of Health and Human Services.

14 “(B) With respect to a request described
15 in subparagraph (A), the Secretary shall reduce
16 the amount of payments under the award in-
17 volved by an amount equal to the costs of de-
18 tailing personnel and the fair market value of
19 any supplies, equipment, or services provided by
20 the Secretary. The Secretary shall, for the pay-
21 ment of expenses incurred in complying with
22 such request, expend the amounts withheld.

23 “(3) APPLICATION FOR AWARD.—The Secretary
24 may make an award of a grant or contract under
25 paragraph (1) only if an application for the award

1 is submitted to the Secretary and the application is
2 in such form, is made in such manner, and contains
3 such agreements, assurances, and information as the
4 Secretary determines to be necessary to carry out
5 the purposes for which the award is to be made.

6 “(d) BIENNIAL REPORT.—Not later than February
7 1 of fiscal year 1998 and of every second such year there-
8 after, the Secretary shall submit to the Committee on
9 Commerce of the House of Representatives, and the Com-
10 mittee on Labor and Human Resources of the Senate, a
11 report that, with respect to the preceding 2 fiscal years—

12 “(1) contains information regarding the inci-
13 dence and prevalence of birth defects and the extent
14 to which birth defects have contributed to the inci-
15 dence and prevalence of infant mortality;

16 “(2) contains information under paragraph (1)
17 that is specific to various racial and ethnic groups
18 (including Hispanics, non-Hispanic whites, Blacks,
19 Native Americans, and Asian Americans);

20 “(3) contains an assessment of the extent to
21 which various approaches of preventing birth defects
22 have been effective;

23 “(4) describes the activities carried out under
24 this section; and

1 “(5) contains any recommendations of the Sec-
2 retary regarding this section.

3 “(e) APPLICABILITY OF PRIVACY LAWS.—The provi-
4 sions of this section shall be subject to the requirements
5 of section 552a of title 5, United States Code. All Federal
6 laws relating to the privacy of information shall apply to
7 the data and information that is collected under this sec-
8 tion.

9 “(f) AUTHORIZATION OF APPROPRIATIONS.—For the
10 purpose of carrying out this section, there are authorized
11 to be appropriated \$30,000,000 for fiscal year 1998,
12 \$40,000,000 for fiscal year 1999, and such sums as may
13 be necessary for each of the fiscal years 2000 and 2001.”.

Passed the Senate June 12, 1997.

Attest:

Secretary.

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